

Executive Summary

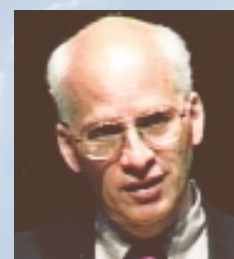
The issues of cancer care in America are everyone's issues. Each day, 34,000 people in America are diagnosed with cancer and another 1,500 die from the disease. Nearly nine million more are living with a cancer history. And every person, regardless of income, education, ethnicity, race, age, or geographic locale, is at risk of developing cancer.

Growing evidence indicates that most people in America receive neither the most appropriate care when faced with a cancer diagnosis, nor adequate cancer prevention and detection services. Factors contributing to this massive failing are many and complex, but the clear and central issue is the failure of our health care system to deliver, in an equitable and timely manner, the cancer care we know is most effective—regardless of a person's insurance status or ability to pay.

The President's Cancer Panel, established by the National Cancer Act of 1971 to monitor implementation of the National Cancer Program, previously reported to the President on this critical “disconnect” between our cancer research discoveries and the type, timeliness, and continuity of cancer care that people actually receive. In 2000 and 2001, the Panel held seven regional meetings to hear firsthand from people with cancer, their families, and the health professionals, administrators, advocates, and volunteers who serve them—393 in all—about problems they experience in accessing and providing cancer care and cancer information. In every corner of the Nation, patients and professionals alike echoed the same moral tenet:

No person in America with cancer should go untreated, experience insurance-related diagnosis or treatment delays that jeopardize survival, or be bankrupted by a cancer diagnosis.

Yet these very things are happening to far too many of us. The problems of cancer care in America are not theoretical, analytic, or abstract—they are real problems affecting real people.



“We need to own up to the fact that when you organize your health care system around a

market-based model and you put it out there for sale, people who do not have the means to pay for it are not going to get good care. It is not intellectually honest to ignore that.”

Gordon Bonnyman, advocate, Tennessee



“...when you are fighting for your life, which I was, it is virtually more than you can do to

also fight the system, but I found I had to fight the system every inch of the way... I also want to point out that I am a middle class person. I have a supportive family. I have an incredible network of friends. I’m also about to serve in my eleventh year in the legislature, so I have skills, and knowledge, and at least perceived power and perceived access to the press that many people don’t have, yet despite all of that, I had an incredible struggle to get what I needed for myself.”

Karen Kitzmiller, stage IV breast cancer patient and state legislator, Vermont (deceased)

What Is Happening to Real People: Findings

The numerous issues described by meeting participants fall broadly into two categories: access and information. In addition, cancer care can be influenced greatly by behaviors and decision-making by both health care providers and the public that stems from perceived differences among populations and individuals.

Barriers Limiting or Preventing Access to Cancer Care

Access barriers include those related to the organization and operation of the health care system itself, financial barriers to care, and physical barriers that reduce or prevent access. However, these categories are not always mutually exclusive.

System Barriers

The current health care system underemphasizes cancer prevention and often allocates cancer funding by disease site. Both approaches are counterproductive to providing comprehensive cancer care and developing effective cancer control programs. Cancer prevention, education, and screening efforts are limited at best and highly uneven across the country. Treatment for detected cancer remains unavailable to some of the uninsured unless they are able to obtain charity care or qualify for medical assistance. In addition, coordination between public payers is poor, and patients often are not informed of all health benefits for which they may be eligible. Believing they have no coverage or limited coverage, patients may incur unnecessary out-of-pocket costs, delay treatment, or even forego care.

System-related barriers to care most often described by people with employer-sponsored or other private health insurance include fragmentation of care, gatekeepers who control access to screening and specialists, and limitations or exclusions on specific drugs and services, including clinical trials. Numerous patients recounted having to fight their insurers to get the care they needed to save their lives. The current system also discourages appropriate end-of-life care, resulting in late referral to hospice (or no referral) and causing many terminal cancer patients to die without adequate pain and other symptom control.

Financial Barriers

Financial Issues Affecting Patient Access to Care. For people with cancer and their families, health care system issues that can be explained logically by fiscal and economic realities often translate into a personal reality that includes family bankruptcy, needless suffering, loss of dignity, and loss of life. Currently, 44 million Americans have no health insurance at all. Uninsured rates are as high as 25 percent of the non-elderly in some states, with much higher rates in some rural and frontier regions.

Many of the cancer survivors and family caregivers providing testimony were self-employed—farmers, ranchers, small business owners, and other independent workers. These speakers explained that they seldom can afford even basic health insurance, though they make enough money to support themselves and their families. The working poor may hold two or three jobs, none offering health benefits. This population is likely to lack both health insurance and the financial reserves to see them through an extended illness. They often avoid cancer screening or care for suspicious symptoms because they know they cannot pay for cancer care. Late stage diagnosis is a common result. When cancer strikes, uninsured workers may find they have too much income or too many assets to qualify for Medicaid or other medical assistance, but are too young for Medicare. These patients can quickly amass huge medical debts that will take the family many years to repay. Some are forced into bankruptcy.

To qualify for Medicaid, patients typically must give up the employment that provides family support and divest themselves of virtually all assets, including their car, home, business, or farm. In addition, survivors described such long delays in obtaining Medicaid approval that they were faced with more advanced disease by the time they were able to begin treatment. Even after securing a Medicaid card, it sometimes took weeks or months to find a provider who would accept Medicaid payment. Cancer patients who remain disabled by their disease for 12 months may qualify for Social Security Income (SSI) payments; however, this income may exceed Medicaid eligibility ceilings, causing them to lose access to cancer care.

At least 31 million non-elderly insured Americans are underinsured for cancer care costs. Though they pay substantial monthly premiums, many find the combined burden of copayments, deductibles, non-covered services,



“For eight months... I went from doctor to doctor to doctor. I had classic symptoms of throat

cancer...what I didn't have was insurance. I was a waitress, \$3.25 an hour, plus tips, on the graveyard shift, in a small community...I was unable to eat, unable to drink. At night I couldn't even swallow my own saliva...I tried to get state aid, but with my large income of \$900 a month, I made too much money. Normally I wouldn't go to the doctor, but I knew I needed care... I paid cash for all of my visits, sometimes taking food out of my children's mouths.”

Catherine Danielson, stage IV throat cancer survivor and single mother of four, Arizona

medical supplies, and drug costs (particularly for oral chemotherapy and supportive medications), slow health plan reimbursements, and additional transportation and child care costs quickly exhausts family savings. This is particularly true when patient income is reduced or lost and/or when a family wage earner must work less in order to care for the cancer patient. Should the patient or spouse lose the job providing health insurance, the family can face a quick descent into indigent care and bankruptcy. Some survivors who return to work but have lapsed insurance coverage may find they are uninsurable, subject to a lengthy waiting period for cancer-related coverage, or eligible only for prohibitively expensive coverage.

Financial Issues Affecting Health Care Providers. As health care payers and purchasers struggle to contain health care costs, financial pressures on health care providers continue to increase, affecting the care available to people with cancer and those in need of screening, diagnostic, and preventive services. Survivors and family members reported widely varied experiences in terms of provider willingness to accommodate patients' lack of insurance or full insurance coverage. Some patients were told to "pay what you can, when you can;" others were able to negotiate reduced rates and payment plans; and some providers donated their time and services. In other cases, however, providers asked for advance payments of \$20,000 to \$100,000 before initiating treatment. These highly divergent responses to patients in need appear to reflect an extreme and intensifying conflict between some providers' commitment to render care as needed and a range of financial pressures that threaten the solvency, vitality, ethics, and integrity of health care institutions and individual providers alike.

Providers described ever-increasing payer-related paperwork that drives up administrative costs and reduces time available to see patients. Shrinking reimbursements and vastly different reimbursements for identical drugs and services in urban versus rural areas threaten the future of community oncology, particularly chemotherapy administered in office settings. These payment differences also are affecting rural providers' capacity to upgrade equipment and staffing to provide more effective therapies in the community. As a radiation oncologist from the Midwest pointed out, *"It costs the same amount of money for me to buy a linear accelerator as it does for somebody in New York City."* Highly disparate reimbursements are forcing ill and fatigued patients to travel long

distances to obtain care they could receive locally if provider reimbursements for that care were equitable in the rural setting. Lack of reimbursement for oral chemotherapy and supportive medications under Medicare and many private health plans also prevents patients from receiving care close to home. Speakers maintained that Medicare and Medicaid reimbursement cuts are increasing the gap between state-of-the-art cancer care and its implementation for all people.

Testimony indicated that diminishing reimbursements also are a key factor driving increased pressure on physicians to see more patients each day. Physicians judged by local health plans to be inefficient may face financial penalties. While providers may suffer reduced revenues and greater stress, patients may suffer more costly losses: inadequate discussion of medical history and all relevant health issues; inadequate patient education; missed opportunities for preventive care; failure to be offered clinical trials or other care that requires additional explanation, monitoring, or paperwork; and in the worst cases, misdiagnoses.

Physical Barriers

Living in rural or frontier areas poses a special set of problems that comprise a vastly underappreciated barrier to cancer care access. Approximately one-fourth of the U.S. population lives in areas designated as rural or frontier, and half of all states have frontier regions (i.e., fewer than 6.6 people per square mile).

Excessive distance from cancer care is due in part to the concentration of health care personnel and resources in urban areas, the lack of public transportation systems in rural and frontier areas, and the fact that many rural and frontier residents lack the resources to travel to care. The scarcity of both primary and specialty care providers in rural and remote areas is a longstanding problem that contributes to late diagnosis of cancer in these populations. Lower reimbursements for care provided in rural settings not related to operating cost differences and limited grant funding to sparsely populated areas continue to hamper efforts to recruit and retain oncologists and other cancer care professionals. Speakers called for incentives to attract health care professionals to these regions and help them sustain careers in underserved areas, including underserved inner cities.

Most rural areas have no public transportation system; patients reported driving up to 300 miles one way for screening or treatment, and some are too ill to do so. Because some services cannot easily be taken to rural areas (e.g., radiation oncology), patients may choose treatment options (e.g., mastectomy versus lumpectomy) that do not require repeated trips to a distant treatment facility. Native Americans, particularly those living on reservations, frequently drive long distances to an Indian Health Service (IHS) hospital or clinic and wait all day to be seen, only to be turned away and told to return the next day. This situation is so discouraging that some avoid seeking care for symptoms until they require emergency care. Many managed care enrollees and Veterans Administration beneficiaries must obtain services from contracted providers distant from the patient's home, sometimes in another state.

Some patients lack reliable transportation or the money for fuel and tolls needed to travel to treatment or screening. Older Americans may not have a family member or friend able to drive them to medical appointments and may be unable to pay for transport. Transportation barriers are particularly onerous for patients in isolated areas such as Alaska, Hawaii, the Virgin Islands, Puerto Rico, and the Pacific Territories, where the only way to reach many, if not all, cancer screening or treatment services is by air or boat; these transportation costs may be prohibitive. In mountain states and rural northern regions of the country, reaching cancer care may become impossible for weeks at a time when roads become impassable due to winter weather. Such conditions can delay cancer diagnosis and disrupt treatment regimens. Telemedicine has the potential to bring some state-of-the-art cancer care services and continuing medical education to geographically isolated areas.

Transportation also is an issue for inner city residents who may not own cars or be able to afford bus or subway fares. In addition, some urban cancer patients are too sick to undertake a trip that may cover few miles but involves multiple bus transfers and considerable walking.

Barriers Related to Information or Education

Lack of information or education, not knowing how to find or evaluate information, not believing or acting appropriately on available information, not knowing how to get needed care within the health system—all can constitute barriers to cancer care.

Provider-Related Information and Education Barriers

Lack of information about cancer and cancer care was the provider-related barrier most commonly cited by those providing testimony at the regional meetings. Speakers emphasized strongly the need to better educate primary care providers about cancer. Initial decisions about care can be a critical determinant of patient outcome, and primary care providers, especially in rural and remote areas, often make these crucial referral and treatment choices.

Considerable disagreement exists, even among oncology professionals, about sometimes conflicting published screening and treatment guidelines. More broadly, there is confusion among providers, payers, and patients as to what constitutes quality care for cancer.

Speakers graphically described the serious repercussions to patients when providers lack reliable current information about cancer care or fail to change practice patterns based on new evidence. Most alarming among these were misdiagnoses that caused lengthy treatment delays, resulted in unnecessary surgery or incorrect treatment, and jeopardized patient survival or quality of life. Speakers also noted that providers may miss signs of cancer in patients with other chronic illnesses or fail to detect depression or other serious health problems in cancer patients. Provider education in these areas, on the care and needs of dying patients, and on cultural differences that affect care were listed among the areas of greatest need in provider education.

Finally, the lack of effective medical data and reminder systems in most clinical settings was cited as a significant reason why some patients “fall through the cracks.”

As one physician observed, “*Medicine currently is less computerized than Wal-Mart.*”

Information and Education Barriers Faced by Patients and the Public


The lack of accurate cancer-related information that is readily available, understandable, clear, and delivered in a sensitive and culturally acceptable manner is a major contributor to the inability of patients and the public to obtain the most appropriate cancer prevention, treatment, and supportive care.

Cancer is perhaps the most feared of diseases. As speakers described vividly, fear of cancer is shared by virtually all



“I said, ‘Well, how would you treat this if I do have [prostate] cancer?’ He said, ‘Well, we’ll just cut that fellow out.’ And I said, ‘What about nerve-sparing surgery? Because, you know I’m kind of a young man, I still like to do some things with my wife.’ He said, ‘Well, you don’t worry about that, just take everything out so you won’t have the cancer. You want to be alive, right?’...I can see that if a person wasn’t educated as to what’s out there they would say this is the end of my sexual life.”

Noah Lewis, kidney and prostate cancer survivor, Louisiana



populations and cultures, and takes the form of fatalism, fear of treatment and its costs, fear of pain and disfigurement, and fear of rejection by one's partner, family, or community. These fears, and enduring myths about cancer, cause many people to reject cancer prevention messages, avoid cancer screening, delay or avoid treatment if diagnosed, and have difficulty understanding and choosing among treatment options or following treatment regimens.

For some Americans, cancer-related information is simply unavailable. Thousands in remote regions and high poverty areas lack telephones and in many areas library access is limited. Some remote areas even lack radio or television reception. Few of the poor own computers or have Internet access. In addition, many people do not go to the doctor or other sites where cancer information is most commonly found. Reaching these populations is a major challenge that some communities are addressing through outreach efforts, church-linked activities, and collaborations with local agencies that provide financial or other assistance.

For many other Americans, available cancer information is unusable due to literacy, language, or cultural barriers. Low literacy appears to be an underappreciated barrier to cancer information and care. Language barriers are a growing challenge to effective cancer communication as the current wave of immigration continues and are a special problem in the clinical setting, where relatives, including children, or strangers are being called upon to translate detailed information about test results or treatment. Speakers reported that some written materials mistakenly have been translated at too high a reading level or in the wrong dialect. Moreover, in some languages, no translation is possible; for example, in some Alaska Native languages, there is no word for cancer. Cancer information also must be presented in a culturally sensitive manner if the messages are to be accepted.

Cancer survivors and health care professionals emphasized repeatedly that regardless of educational level, income, or insurance status, people need help finding and evaluating accurate, up-to-date cancer information and navigating the complex and fragmented health care system. Communities are attempting to address this need by training community members to be outreach workers and cancer educators and by establishing "patient navigator" programs in hospitals and other treatment facilities to help people access medical and financial assistance for which they may qualify and secure the care they need. While the need for such programs

for insured and uninsured patients at all educational and socioeconomic levels was unquestioned, the tenuous stability of these often fledgling programs was also underscored.

Finally, speakers indicated that cancer surveillance is grossly underfunded in many areas of the country. Without adequate information on the extent and nature of the cancer burden, states cannot identify high risk groups, focus their planning efforts, develop targeted prevention and cancer control efforts, or evaluate their success. Local data on cancer patterns and trends may take years to accumulate, but these activities should proceed in tandem with action to address readily apparent cancer control problems.

The Impact of Culture and Bias on Cancer Care

Disparities in cancer treatment and disease outcome between various population groups are being documented with increasing frequency and clarity. A considerable number of speakers recounted experiences in which they or others received—or did not receive—cancer information or care for reasons stemming from cultural or racial differences, and biases these differences engendered. Importantly, bias that results in negative health outcomes can originate from both patients and health care providers.

Issues of Culture and Bias Originating With Patients and the Public

Cultural perspectives or biases may cause individuals to avoid cancer screening or treatment, or otherwise make decisions that may adversely affect their survival and quality of life. These biases can also have a positive impact on health. They affect the ways in which people perceive illness, how they develop and act on medical and caregiver preferences including folk healing methods, how they explain and tolerate pain, and what they perceive to be quality care. As numerous speakers indicated, however, fatalism about cancer remains pervasive in many cultures, though it takes different forms in different cultural groups. Old myths about cancer also persist in many populations.

The grinding circumstances and resulting culture of poverty profoundly affect the information and care-seeking behaviors of the poor. Rural residence and agricultural lifestyle also comprise a distinct culture in which it is rare to seek medical care unless one is in significant pain. Many rural residents, some of whom are poor, are uninsured and do not believe in

going to the doctor unless they can pay the bill. In addition, farming women are unlikely to interrupt farm routines to seek medical care, even when they have symptoms. Similarly, speakers suggested that the cultural importance of fulfilling one's role in the family causes many Asian women to minimize their own health needs and avoid out-of-pocket health care expenditures.

Provider-patient relationships built on familiarity and trust are crucial to effective education and medical care for some populations, notably Native Americans and a number of recent immigrant populations. Yet the medical facilities at which these populations typically receive care are staffed by temporary duty doctors who often are of different cultures or lack sensitivity to the cultures of their patients. In some cases, resistance to entering the health care system and difficulty navigating it are undergirded by cultural traditions that consider assertiveness, particularly with authority figures, to be inappropriate or rude. Speakers testified to the critical need for health care providers from minority and underserved populations. In addition, traditions concerning female modesty and the acceptability of female patients being examined by male physicians underscored the need for more female health care providers.

Distrust of the health care system generally is common, particularly among populations that historically have been targets of discrimination. Many people fear being used as “guinea pigs” by medical practitioners. This distrust reinforces the fear of cancer treatment, including clinical trials, and remains a significant barrier to appropriate cancer care.

Secrecy about cancer remains prevalent in some populations, with patients hiding their disease even from partners and other family members. In some Asian cultures, knowledge of a cancer diagnosis still is withheld from the patient. These cultural prohibitions can make it extremely difficult to reach people with needed cancer information and care.

Issues of Culture and Bias Originating With Health Care Providers

Bias, either overt or unintended, also can originate with health care providers and administrators who may make decisions or recommendations that are not in the patient's best interest. Physicians in particular have a special responsibility to be sensitive to their own cultural mindsets and biases, as well as those of their patients, because of the power and authority many patients confer upon their doctors. Speakers testified to pervasive and often overt provider bias against gay and lesbian patients that causes these patients to avoid screening and care. Patients with disabilities may experience unintended bias when they are not offered screening or other cancer-related care because providers focus only on health issues related to the disability. In other cases, providers may not share clinical information with patients who they assume will not understand it, or may fail to offer treatment regimens they assume patients will be unable to follow.

Numerous speakers indicated that bias at the provider and institutional levels also may occur when assistance, referrals, treatment, and other services are more readily offered to more educated or white patients compared with less educated or minority patients, even when they have equivalent resources, or lack of them. Some disparate behavior may be intentional, but according to speakers, more often reflects biases transparent to the providers themselves.

In addition, presenters described instances in which culturally insensitive behavior on the part of providers reflected a simple lack of education about other cultures and customs or an unwillingness to accommodate non-medical traditional practices that would not interfere with treatment but would comfort the patient.

What Can Be Done to Help People Now: Recommendations

The President's Cancer Panel is acutely aware that the issues and problems described in this report are not being expressed for the first time. Indeed, the very fact that these problems—faced by real people with cancer every day, in every corner of the Nation—remain so prevalent makes concrete, achievable action to resolve them that much more urgent.

Access to appropriate cancer care is the crucial, fundamental step needed to relieve the desperate physical suffering, financial devastation, and loss of dignity so many people endure when cancer is diagnosed. If we lack the political will to craft and implement a National plan to address this unacceptable situation, then incremental steps must be taken to quickly remedy health care financing and delivery system elements that result in so much of the needless distress now experienced by cancer patients and survivors, and their families.

Continued research on the quality and equity of cancer care, outcome disparities, and related health economics and system issues is essential to guide transformation of the health care system in the coming years to better serve the public. But the people with cancer today, and their families, cannot wait for this distant relief. The President's Cancer Panel recommends:


Immediate Action Steps

1. Provide immediate medical coverage for the uninsured—84 percent of whom are workers and their dependents—upon a diagnosis of cancer to help ensure that no person with this disease goes untreated.
2. Address health coverage issues that contribute substantially to the financial devastation of people underinsured for cancer care costs:
 - Provide reimbursement for anti-cancer agents, supportive medications (e.g., antiemetics, pain medications), and proven chemopreventive agents, regardless of method of administration.

- Within two years, public and private payers should reach consensus on and implement a standard health benefit package for cancer care. This benefit package should be based on the best available medical evidence and should be updated regularly to reflect advances in the standard of care. The reports and deliberations of the Institute of Medicine, other groups, and consumers should be used to inform this effort.
3. Address patient and public needs for cancer information and for assistance in accessing services:
 - Provide funding to help communities coordinate, promote, and support community-based programs, including patient navigator programs, that help people obtain cancer information, screening, treatment, and supportive services.
 - Recognize that the services of non-physician personnel who are trained to conduct cancer screening, and provide cancer education and case management in varied settings are an important component of cancer care that should be reimbursed.
 4. Sustain cancer care in the community by providing consistent and realistic health care provider reimbursement across states, and between urban and rural locations within states, for the cost of chemotherapy drugs and their administration.

Longer-Term Solutions

1. Medicare, Medicaid, the Veterans Administration, the Department of Defense, the Indian Health Service, and other public payers should clarify the order of responsibility for payment for cancer care services when individual patients are eligible for benefits under more than one program. This information should be communicated promptly and clearly to those who provide cancer care services and assist patients in navigating the health care system. The existing Quality Interagency Coordination Task Force may provide a forum for accomplishing this important task.

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2. Develop Federal policies to minimize bias in the provision of cancer care:
 - Raise awareness of unintended or overt bias through initial and continuing training of health care professionals at all levels, as well as administrators and others who make decisions affecting patient care.
 - Establish and implement systems for monitoring treatment equity. In addition, expand quality of care research to include issues of treatment equity.
 3. Minimize disparities in the provision of cancer care by:
 - Educating primary care providers about cancer.
 - Educating all cancer care professionals about the nature and application of evidence-based medicine and about clinical trials.
 - Developing and disseminating better tools to assist health care providers in conveying information about cancer and about cancer care options.
 4. Address the problems of temporary medical staffing and cultural incompatibility by establishing additional mechanisms to encourage more minorities and members of other underserved populations to enter cancer care professions. Provide incentives to encourage providers to practice in medically underserved areas.
 5. Extend state-of-the-art cancer care to rural, frontier, and other underserved areas by expanding the use of telemedicine and providing a reimbursement system that facilitates expansion of telemedicine to geographically underserved areas.
 6. Permit more flexible use of categorical funding where appropriate to enable states to fashion more rational and more comprehensive cancer control programs.